MetroChicago Health Information Exchange

Introduction

Good afternoon, Mr. Chairman and members of the committee. I am Marilyn Lamar, outside counsel to the Metropolitan Chicago Healthcare Council and MetroChicago Health Information Exchange. I would like to thank you for the opportunity to testify and for your leadership on promoting secure health information technology in the State of Illinois.

The Metropolitan Chicago Healthcare Council (MCHC) has been working for the last two years to launch a regional health information exchange - the MetroChicago Health Information Exchange (HIE). As the membership association for hospitals and health care organizations in the greater Chicago region, MCHC is uniquely positioned to stand up an HIE with a great deal of support from its members. The MetroChicago HIE is operated by MCHC-Chicago Hospital Council, an affiliate of MCHC.

MCHC appreciates this opportunity to present testimony regarding how behavioral health information may be better integrated into HIEs in Illinois. Illinois law regarding confidentiality of mental health and developmental disability information[1] presents great difficulty for use of such information in an HIE because patients are not allowed to sign a consent for disclosure of mental health information to any subsequent care provider who may need it. Instead, patients are only permitted to consent to disclosure from one care provider to another specific care provider and the consent must expire on a specific calendar date. These and other provisions of Illinois law make it virtually impossible for mental health or development disability information to be included in an HIE without running the risk of violating Illinois law.

MCHC is concerned that Illinois law is resulting in the exclusion from HIEs of prescription drug and other important clinical information from the records of mental health and developmental disability patients. This may in turn result in these patients receiving care that is of a lower quality than they would receive if this information were included. This is especially true as medications are increasingly used to treat behavioral health conditions. The restrictions of Illinois law may lead to a "digital divide" that adversely affects mental health and developmental disability patients.

Health care providers have long noted the compliance challenges of this Illinois law whether their records are on paper or in electronic health record (EHR) systems. Participants in HIEs are spending significant time and money on custom programming and other strategies to comply with Illinois law by filtering mental health and developmental disability information so it is not sent to an HIE. In light of the broad language used in Illinois law and the limitations of current technology, there are also concerns as to whether the filtering is thorough enough and, in some cases, whether too much information is being excluded by the filters.

[1] Mental Health and Developmental Disabilities Confidentiality Act, 740 ILCS 110

Privacy of medical information is important in the HIE context but it needs to be balanced with the use of technology to improve clinical care. In MCHC's view, it would be appropriate to treat mental health and developmental disability information like other protected health information under the HIPAA Privacy Rule as discussed below. MCHC appreciates the opportunity to be part of the discussion of these important issues.

The MetroChicago HIE is described below to provide context for this testimony.

The MetroChicago HIE is a secure, electronic way for participating hospitals, doctors and other authorized caregivers to access a patient's medical records from others that participate in the HIE. The HIE should help doctors and hospitals provide safer, quality health care faster. More than 80 percent of hospitals in the metropolitan Chicago area have signed on to be founding members of the HIE - a true testament to these hospitals' dedication to improving patient care and safety through technology.

By participating in the MetroChicago HIE, doctors can have quick access to patients' medical records from other participating health care providers. This makes it easier for doctors to view a patient's health history and lab tests, even if they were done at a different hospital, clinic or emergency room. With the HIE, doctors can spend more time with patients and less time searching for their information. Also, in emergencies, it allows caregivers to access vital information about a patient that could be life saving. The MetroChicago HIE should also help to control health care costs by reducing unnecessary tests and treatments.

By having access to records of care provided by other participants in the MetroChicago HIE, doctors can provide their patients with coordinated care wherever they go. Care should not be delayed searching for information from others providers who participate. It is also less likely that tests will need to be repeated. A patient may go to a clinic for a routine physical, a hospital specialist for diabetes maintenance and a to another hospital's Emergency Department for care with symptoms of a stroke. Through the HIE, all participating health care providers will be able to access the same information about the patient to provide them with the best possible care based on their health history.

Care providers using an HIE will usually be able to see information about a patient's:

- Allergies
- Medications
- Immunizations
- Doctor visit records
- Emergency room records
- Hospital Reports
- Test results
- Diagnoses

We expect that using HIEs will provide faster and more complete access to patient information so that

providers can make better informed decisions about treatment plans. Patients can elect to opt-out and not allow their medical information to be available through the MetroChicago HIE. It is not a condition of receiving care.

Health information disclosed to HIEs may include information regarding patient demographics, problem lists, allergies and medication lists, radiology reports, and lab reports. However, under current law, if a patient received certain mental health, developmental disability or substance abuse treatment services, that information will be excluded from the MetroChicago HIE. In addition, unless a patient signs a separate consent, certain information about genetic testing or HIV/AIDS will not be available through the MetroChicago HIE.

The impact of Illinois law restrictions on disclosure of mental health and developmental disability information in the HIE context is discussed below. State and federal limitations on disclosure of information from substance abuse treatment centers present similar issues but are not addressed in this testimony.

Federal and State Law Affecting Disclosure of Patient Information through an HIE

The MetroChicago HIE has been structured to comply with federal and state privacy and security laws. Use of MetroChicago HIE is limited to authorized users who confirm that they will comply with these laws. Per the State of Illinois' plan to create a statewide network of HIEs, we expect that similar restrictions will apply to other HIEs that the MetroChicago HIE may link to in the future.

Federal privacy regulations that apply to HIE participants include the Privacy Rule[2] adopted under the Health Insurance Portability and Accountability Act of 1996 (HIPAA). The HIPAA Privacy Rule allows a patient's protected health information (PHI) to be used and disclosed without patient consent only for treatment, payment and certain health care operations, subject to specific exceptions. One of these exceptions requires a written authorization of the patient for disclosure of "psychotherapy notes" which are generally defined as the mental health professional's notes regarding a conversation with a patient in a counseling session. However, the HIPAA Privacy Rule does not require patient authorization for disclosure of a patient's mental health diagnosis, care plan and medications.[3]

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[2] 42 CFR Parts 160 and 164.

[3] The HIPAA Privacy Rule defines psychotherapy notes as "notes recorded (in any medium) by a health care provider who is a mental health professional documenting or analyzing the contents of conversation during a private counseling session or a group, joint, or family counseling session and that are separated from the rest of the individual's medical record. Psychotherapy notes excludes medication prescription and monitoring, counseling session start and stop times, the modalities and frequencies of treatment furnished, results of clinical tests, and any summary of the following items: Diagnosis, functional status, the treatment plan, symptoms, prognosis, and progress to date." 45 C.F.R. § 164.501.

Unlike the HIPAA Privacy Rule, the Illinois Mental Health and Developmental Disabilities Confidentiality Act (IMHDDCA) does not permit disclosure of a broad category of records and communications about mental health and developmental disability services (sometimes referred to as mental health and developmental disability information or MHDDI). For example, MHDDI would typically include the diagnosis and medications prescribed for a patient, which is significantly broader than the psychotherapy notes that require authorization under HIPAA. In addition to the mental health professionals who are the focus of the HIPAA provision, the Illinois statute restricts disclosure of MHDDI created by physicians (including primary care physicians) and nurses as well as psychiatrists, psychologists and social workers.

The IMHDDCA allows a patient to consent to some disclosures but it imposes conditions that do not work well for HIEs. These include the need to specify each of the following in the consent:

- the recipient;
- the purpose of the disclosure;
- the nature of the information to be disclosed; and
- a calendar date on which the consent will expire.

The need to specify the recipient means that a general or "blanket" consent to disclose mental health and developmental disability information to all providers who may in the future treat the patient would not be permitted even if the patient wished to grant such a consent. A provider who receives such information under a proper consent is prohibited from disclosing it further without another consent.

It may also be difficult to predict in advance the purpose of the disclosure and the nature of information that needs to be disclosed. The need to specify an expiration date presents practical issues of how it could later be deleted from an EHR as of that date and the problems that may arise if the patient or the provider forgets that certain information is no longer in the EHR after a specific date.

In order to comply with these requirements, participants in the MetroChicago HIE have been asked to exclude MHDDI from the electronic records that they make available through the HIE because it does not appear possible to have a patient consent that would be effective to allow use of MHDDI by all later providers who might treat the patient.

A. Possible Adverse Impact on Quality of Care

The possible disparity in care that results from excluding such information is illustrated by the following case studies:

Case Study # 1 - HIE facilitates care
A grandmother has a fall and a suspected fracture. She has a history of diabetes and irregular heartbeat. The EMTs preparing to transport Grandma to the Emergency Department asked the family what

medications Grandma was taking and were handed a brown paper bag with approximately 20 pill bottles. No one knew what Grandma was actually currently taking, when they might have been refilled, or any background on recent prescriptions. The ED was not affiliated with the hospital or the primary care provider grandma usually visited and had no prescription history for her. Grandma's hip fracture, surgery and rehab require care coordination and communication with her regular physician and her family in order to provide high quality care and avoid complications that might result in readmission to the hospital. Access to her ED records by later care providers using the HIE makes this coordination more efficient.

By using the HIE, the ED physician and nurse would be able to view records of Grandma's previous care from the cardiologist and endocrinologist she has seen, her latest lab and radiology reports, and, most importantly, what medications she takes and what allergies she has. She was also diagnosed with a urinary tract infection. An adverse drug event was avoided because the hospital physician used the HIE and became aware that Grandma had a strong allergy to sulfa drugs which might otherwise have been used to treat the infection. Instead she was prescribed antibiotics.

Case Study # 2 – Withholding information causes disparity of care

The patient is a 38 year -old male with schizophrenia with acute anxiety who is on public aid. The patient goes to several clinics and a psychiatrist on an irregular basis. Complaining of anxiety, the patient drinks excessive caffeine, smokes continually and paces the floor. Unable to control his anxiety, the patient heads to the Emergency Department. The patient is already on ten different medications, with doses changing constantly. The attending physician has no access to a complete list of medications through the HIE because under Illinois law, some of them have been prescribed for mental health purposes so could not be made available through the HIE. Even if the patient wanted to consent to have his psychiatric medications available to future ED providers through the HIE, Illinois law would not allow such a "blanket" consent.

The ED physician knows very little about the patient's history and prescribed anti-anxiety medication. The patient's wife subsequently finds him dead on the floor the next morning. The Coroner finds the cause of death was a heart attack with adverse drug interaction contributing to the patient's death.

These situations are relatively common and place a great burden on the hospitals and physicians who are trying to provide the best care possible with minimal patient information. Because current Illinois law causes withholding of behavioral health information from the medical records available through HIEs, patients are put at a greater risk of adverse events, harmful drug interactions and delayed care.

Without historical patient information, physicians are often forced to repeat unpleasant or costly tests and procedures. For example, if a patient presents to an Emergency Department with shortness of breath and chest pain, the attending physician may order an electrocardiogram to rule out a heart attack. However, had the patient's information been available through an HIE, the doctor could have seen that the patient has a history of acute anxiety attacks and that anxiety was likely to have caused those symptoms. This information would have allowed the physician to quickly address the patient's

symptoms without subjecting him to an expensive EKG which may have led to more anxiety. The MetroChicago HIE will allow authorized care providers to securely access approved patient information to provide safe, quality and timely care to their patients.

B. Technical Issues in Excluding Mental Health and Development Disability Information

The MetroChicago HIE is designed to facilitate the secure exchange of patient data between hospitals and other health care providers. Hospitals typically send 4 types of messages: 1) ADT messages that contain patient names, demographic and insurance information, 2) lab test results, 3) radiology/ x-ray reports, as dictated by the radiologist and 4) general narrative text documents including, medical history, physical, operative reports, consult reports and discharge summaries and instructions that can be used for the patient's continuing care plan and medication list.

Physician EHRs send similar patient ADT information and visit summaries. The HIE receives these messages and aggregates the information into a composite record of the patient. Providers and hospitals can view that data by viewing the patient's record via a web page or by downloading what is called a CCD message – or Continuity of Care Document which is a comprehensive profile of the patient's health status.

EMR systems are designed to transmit data as soon as an event occurs so:

(1) Each transmission is an isolated event and it is very hard to apply decision rules to determine whether a particular message should or should not be sent based on data from elsewhere in the system.

(2) These are the actual reports that comprise the legal medical record and as such must comply with standards for completeness and accuracy. There is no process for summarizing, abstracting or redacting information in preparation for sharing outside the organization. As soon as it is signed it is transmitted.

HIEs work well for patients whose health care histories and illnesses fit comfortably into HIPAA's provisions for disclosures without consent for treatment, payment and operations. Additionally, the MetroChicago HIE provides the patient with an opportunity to "opt-out" meaning that they can elect to not have their information be visible through the MetroChicago HIE to providers who are caring for them.

Other Illinois laws require consent for disclosure of HIV/AIDS information and genetic testing information so health care providers are required to obtain a specific patient consent before making such information available through the MetroChicago HIE. However, the consent requirements under these laws are not as difficult to satisfy in the HIE context, so HIV/AIDS and genetic testing information will not be excluded from an HIE if the patient consents (unlike a patient who desires to consent to disclosure of MHDDI through an HIE but Illinois law does not provide a workable path to do so).

Compliance with the IMHDDCA is further complicated because the definition of what constitutes MHDDI is not entirely clear. A treating professional's notes are clearly MHDDI subject to the special consent requirements, but it is less clear whether references to a history of a behavioral health issues in a consult report satisfies the definition because it depends on whether it was recorded in the course of providing mental health or developmental disability services. This may be difficult to determine from a paper or an electronic record.

As a result, MetroChicago HIE participants have spent significant time and resources to filter out MHDDI and develop other strategies for compliance. The following are examples of problems encountered by participants in the MetroChicago HIE in trying to implement the requirements of the IMHDDCA.

If consults dictated by all behavioral health providers were filtered out, it may filter out care provided by a mental health professional to a patient who does not have a mental health condition. For example, an evaluation for competence to sign a consent form for a surgical procedure may determine that the patient is competent. Should that record be blocked simply because it was created by a mental health professional?

Another approach would be to develop a list of diagnosis codes to block the related record from being transmitted to the HIE. However those codes often are not assigned for 7 to 10 days after discharge so transmissions would need to be delayed for all patients (with or without behavioral health concerns) until the coding process was complete. This means the data might not be available when the patient sees his or her doctor for follow-up after an ED visit or a hospitalization – which undercuts an important benefit of an HIE

The participant could also create a list of medications that are frequently prescribed to control behavioral health conditions and block transmission of those records. However, as a group, behavioral health medications have more drug-to-drug interactions so blocking transmission of these records means that the next provider may prescribe a drug that interacts with medications already prescribed because the provider would not see the full list. This puts the patient at risk of physical harm from drug-drug interactions and it may delay care while the provider seeks the information from the previous provider – assuming they can even identify the previous provider because his records would not be in the HIE either.

Narrative text documents may present the biggest challenge. Technically, it is very difficult for a computer to evaluate whether a free text document is describing a behavioral health condition. A filter for key words might be used to describe a behavioral health condition but there are a lot of words to check and it would be necessary to evaluate how the word is used. For example, "history of depression" and "no history of depression" both use the term "depression." The word might describe a behavioral health condition but disclosing a record that contains the first phrase might be illegal while disclosing the second phrase is not illegal. It is also difficult to tell the computer to distinguish between those two phrases and the phrase "depression of the skull" when used to describe a head injury.

References to behavioral health issues in a family history may also present problems. For example a patient's record might contain the phrase "the patient's mother has a history of depression and suicidal behavior and therefore patient should not be discharged into the mother's care." Should the reference to the mother's depression block transmission of that record even though the patient has no such history and is being treated for a broken leg? This is very difficult technically.

Given the current state of Illinois law, providers may decide they are unable to send most text documents for any patients – behavioral health or otherwise – which would create huge gaps in the records of all patients – including those patients who don't have any behavioral health issues. This is a situation in which the IMHDDCA could harm non- behavioral health patients, decreasing the value of HIE for **all** patients.

It should be noted that in 2014, under the EHR incentive program established by the American Recovery and Reinvestment Act of 2009 (ARRA), both physicians and hospitals will be required to exchange health information including medication lists, problem lists and narrative text documents such as care summaries, discharge instructions and discharge summaries in order to receive incentive payments and, starting in 2015, to avoid reductions in Medicare reimbursement. It is critical to revise Illinois law so that Illinois physicians and hospitals will be able to fully comply with the Meaningful Use requirements established by ARRA.

It should also be noted that implementing the type of filtering just described requires highly sophisticated software programming and substantial computing power. This means that physicians and hospitals would have to spend literally hundreds of thousands of dollars in hardware, software and programming staff time to help ensure they comply with the current laws. This expense and staff effort is an unreasonable expenditure for hospitals to bear. It would be virtually impossible for physicians other than the largest physician group practices. Accordingly, the IMHDDCA creates a significant barrier to provider and hospital participation in HIE.

Conclusion

The behavioral health patient population is particularly vulnerable in a health care delivery system in which care is provided by multiple unrelated providers with separate EHRs. The patients frequently lack resources and support systems and they may not be sufficiently organized to bring an accurate medical history to their next health care encounter. This population is one that could benefit most from consistent, coordinated care and case management that would be possible if the providers caring for them could have access to all of the patient's medical records through an HIE. However, the restrictions imposed by laws written long before electronic health information exchange was even contemplated have caused the MetroChicago HIE to ask its participants to not transmit mental health and developmental disability information. This may ultimately result in the exclusion of a significant amount of data as an increasing percentage of the population takes medication for behavioral health problems

The current IMHDDCA, designed with the best of intentions to protect the interests of a vulnerable population, may actually work against the individuals it was designed to protect when it is applied in the HIE context. Unless it is changed, the current law will prevent behavioral health patients from receiving the benefits that an HIE will provide to other patients. Behavioral health patients will wind up on the wrong side of the digital divide.

We recommend that the HIPAA Privacy Rule be the basis for disclosure of all mental health and developmental disability information in all contexts in Illinois, including all HIEs. A patient's authorization will continue to be required for disclosure of psychotherapy notes. Most mental health providers keep these notes separately so this should not present the filtering issues described above.

Thank you for your time.

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